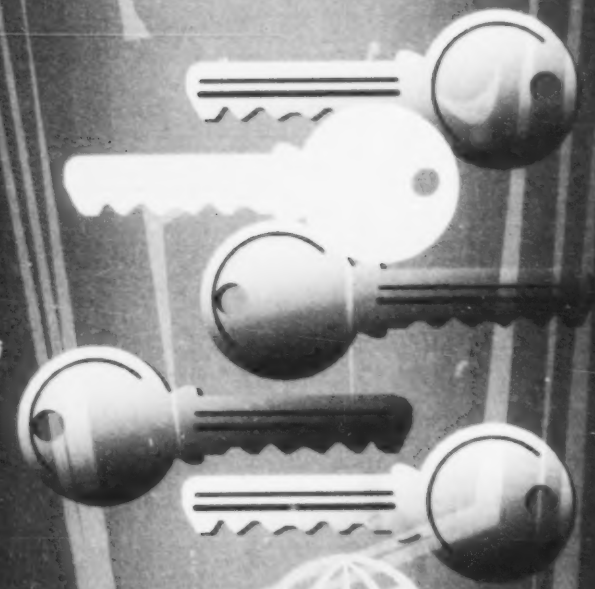
# Opening Doors

*Turning Policy Keys on Disability Supports*



L'INSTITUT ROEHER INSTITUTE

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## How to use this handbook

The federal, provincial and territorial governments called for a new "policy blueprint" for persons with disabilities in their joint accord *In Unison: A Canadian Approach to Disability Issues.*

The Roeher Institute has responded with its 2002 research report *Moving 'In Unison' into Action: Towards a Policy Strategy for Improving Access to Disability Supports.*

This handbook summarizes the key findings and recommendations of our research. It is designed to help Canadians with disabilities, those who support them, and concerned organizations, communities and individuals focus their input into this important public policy process.

There are three main sections in the handbook, representing three key stakeholders: persons with disabilities, families and communities. Each section includes a brief introduction, facts from the research and key policy issues.

The last section recommends avenues for action and a list of key resources and contacts.

Lack of support increases the impact of disability on the lives of persons, their families and communities. And lack of support makes Canada's commitment to equality and human rights for persons with disabilities ring hollow. It is time to move beyond "policy blueprints" to a new reality – a new equality.

Cameron Crawford
President
The Roeher Institute

## Overview

Disability is not about the few, but the many. Disability is not about them: it is about us. And disability supports are not about charity: they are about human rights, as the Supreme Court of Canada has made clear in the Eldridge decision.

At least one in five Canadians is directly affected by disability. They either have a disability or care daily for someone who does. That's some seven million Canadians. And the number is growing – for many reasons.

Our largest age group – the Baby Boom – is passing from mid-life to senior status, and the incidence of disability increases as we age. And, not only are Canadians living longer but we want to live longer independently.

The population living with disability, and their caregivers, is also constantly changing. Not only do the needs of persons with disabilities change, but so do the actual persons. Our research shows that as many as 3 in 10 persons with disabilities in a given year either did not have a disability the year before or will not have one the next.

Our research also shows that large numbers of persons with disabilities are not receiving the supports they need. "Lack of support specific to disability is for many people inseparable from social and economic exclusion – unemployment, poverty and isolation."

The existing patchwork of support systems places a great deal of stress on those it seeks to serve and notoriously allows persons in need to fall through its cracks. People must try to fit into a bewildering array of programs with eligibility criteria that typically restrict rather than improve access — if the support or service is even available.

This piecemeal system tends to break down just when it is needed most by persons with disabilities – at key transition points in their lives. These include the transition from diagnosis to living with disability, elementary to high school, school to work, and to living independently.

It is clear we need more resources for supports for persons with disabilities and more effective use of resources. We need a co-ordinated *customer-driven* policy strategy. In this new approach, persons with disabilities and their families can exercise the best options for their needs from a range of choices.

Canadians need a fluid, seamless, national support system that cares for the whole life of the person and offers them appropriate levels and kinds of support throughout their changing lifespan. We need a comprehensive, coordinated and portable support system that treats persons with disabilities like whole persons and full citizens.

Canada has made a commitment to the human rights, citizenship and inclusion of persons with disabilities – and has taken many first steps. It is time to move to the next level: respecting persons with disabilities and their families as active experts on their own lives and placing them at the centre of support systems rather than on the receiving end.

> The consistent message from focus groups across the country is that without adequate supports and services, particularly around transition points in their lives, people with disabilities and their families endure unnecessary hardship and are disenfranchised from full and active participation in the social and economic lives of their families, communities and country.
>
> *Moving In Unison Into Action,* The Roeher Institute

# PERSONS WITH DISABILITIES

## Introduction

One of the key findings of our research is that many persons with disabilities in Canada are not receiving the supports they need to ensure their optimal health and development. In other words, there is a significant gap between the disability supports people need and what they actually receive.

The extent of these unmet needs varies according to factors such as the kind and severity of disability, employment status, family income, location, age and sex.

Access issues are even more complex for persons of First Nations communities and visible minorities. Also, little information is available about the needs gap for children.

Our research provided a profile of adults who have the greatest unmet needs for aids and devices or help with everyday activities. They are likely to:

- be of working age; and have
- moderate or severe disabilities;
- lower income;
- little income from paid employment; and
- no disability-income support or benefits.

**Disability support:** *Any good, service or environmental adaptation that assists persons with disabilities to overcome limitations in carrying out activities of daily living and in participating in the social, economic, political and cultural life of the community.*

The Roeher Institute

## Facts about Persons with Disabilities

- Less than half of the two million adults who need help with everyday activities because of disability have all the assistance they need.
- Unmet needs include help with grocery shopping, housework, heavy household chores, meal preparation and personal finances.
- Generally, people needing aids and devices have what they require. However, nearly 20% of adults need more aids than they have and 11% need aids and have none.
- Items most widely needed: hearing aids and volume control telephones; glasses, contact lenses and magnifiers; canes, wheelchairs, arm/back/leg braces.
- One quarter of the 254,000 adults who need external home modifications have none. Half of the 219,000 adults who need indoor modifications have none.
- Nearly one third of the two million adults with disabilities who pay for regular medication get no reimbursement from a public or private health plan.

Note: Key data sources include General Social Survey on Community and Social Support, 1996; Health and Activity Limitations Survey, 1991; National Longtitudinal Survey of Children and Youth, 1998.

## Policy Keys for Persons with Disabilities

### 1. A system to identify, assess, plan and coordinate needed supports

Across the country, persons with disabilities expressed the clear need for a coordinated, holistic approach to personalized needs assessments, planning and coordination.

Lack of coordination reaches across provinces, ministries, communities, the employment system, community agencies and families. Persons with disabilities who move may take months to qualify for and receive supports and services in their new community – if they are even available.

We need a Canada-wide policy framework or set of funding commitments so that persons with disabilities can receive equitable supports and services in any and all parts of the country. Without a portable system, the mobility rights of persons with disabilities are compromised.

People interviewed also spoke about the need for a central information source or an organized point of contact to link up with the system of support services. Now, persons with disabilities who need assistance are usually on their own or must rely on family members to find and arrange help. This can result in difficulties and delays in finding supports.

Research participants emphasized the importance of an ongoing team or partnership approach, especially for children with disabilities and especially through key transition points. Now, families must typically assume planning and coordination duties on top of daily care.

## 2. Eligibility criteria

Eligibility determination emerged in the research as a crucial issue for persons with disabilities. Criteria often result in a restriction of options and opportunities at all stages and phases of their lives, compounding the stresses and challenges they already face because of their disability.

Restricted and inflexible eligibility criteria were identified across the whole range of agencies and ministries involved with supports and financial resources. A person may feel pressured to exaggerate a disability to qualify for in-home assistance; or forego a training program that requires full-time attendance because they have the stamina to go part-time only; or be unable to afford a power wheelchair due to low employment income while someone on social assistance may have it largely covered as an in-kind benefit. The end result is that people are simply unable to qualify for and/or get the supports they need.

A defining problem is that eligibility criteria are typically locked to factors such as age, income, nature or "severity" of the disability rather than to the situation, circumstances and needs of the individual. The system needs to be turned on its head toward a customer-driven approach.

## 3. Access to personal disability supports — in-home, community, developmental, school and employment

Focus groups consistently identified lack of access to disability supports as a major problem. A support may simply be unavailable in an area or community. Or it may not be within convenient distance, or involve reliance on inadequate or non-existent transportation, or waiting lists and delays. In effect, the support is not available in any practical sense.

There can be a "constant battle" by persons with disabilities and family members for basic entry to programs and inclusion and integration in social and economic opportunities around each transition point, and thereafter.

## 4. Affordability of supports and services

Costs put disability supports and services out of practical reach for many persons with disabilities.

In many cases, a person qualifies for a given support, but may be unable to afford it, e.g. unable to afford a co-payment for a publicly subsidized support. The cost of specialized supports was also consistently reported as a major factor impeding access to needed supports.

For many persons with disabilities the effect of the extra costs of needed supports is compounded by low incomes — often the result of inadequate financial and labour market supports.

## 5. Supports for persons with disabilities to live independently in the community

Focus groups reported that putting persons with disabilities in institutions or outside their families is on the rise because it can be so hard to get needed supports in the community.

For example, parents may be refused modest income support and directed to public care for their children. Or adults may be forced into congregate living places due to the severe lack of affordable or subsidized housing.

Available statistical data tend to confirm continued reliance on institutionalization. The figures suggest that, although governments *say* they are committed to more personalized approaches to support outside of institutions, actual progress has been slow.

# FAMILIES

## Introduction

Our research found that just 5% of the 1.854 million adults with disabilities who need support with everyday activities because of disability receive all the help they need and are receiving supports and services from community agencies at no net cost to themselves.

Families struggle to fill the gap. Or, more accurately, the chasm.

Family members are the backbone of the disability support system in Canada. They account for almost three out of four care providers. They rely on extended family members, friends and out-of-pocket expenditures to support their own efforts.

Typically, family members also have to plan, negotiate and co-ordinate supports as well as provide daily care. This added responsibility is onerous for many families who find themselves "on duty" 24 hours a day, 365 days a year. As one person interviewed put it so bluntly and eloquently: "Only the professional is given a chair to rest on."

Canadians need measures that respect families' willingness to invest in their own members but also support families and their overall health, development and social inclusion.

### *The price of commitment*

People who give 20 hours a week of disability-related help to a family member have an average household income of $38,020 and 5.8 close friends. People who do not provide such help average $47,610 and 7.5 friends.

General Social Survey on Community and Social Support, 1996.

## Facts about Families

- Family members who have no outside help respond to the needs of 49% (about 900,000) of persons who need support.
- Family members help another 23% (418,000) with assistance from friends or community agencies.
- Most caregivers are women (60%); most are under age 45.
- Those helped are mainly parents (44%), then spouse/partner (30%), and children (17%).
- On average family members invest 316 hours per year assisting those with disabilities, the equivalent of 40 eight-hour workdays.
- Almost one million family members are primary caregivers and expect to help indefinitely.
- In 60% of cases where family members are primary caregivers, no one steps in when they need to take a break.
- People who help family members and who need support to continue helping are more likely to report poor or fair personal health, and to have a disability themselves.

## Policy Keys for Families

### 1. Recognition and support for contributions families make to the disability supports system

By and large, people who help family members with needs arising from disability do so willingly. Yet, one in five feel some degree of "burden," one in four report their health has been affected, and one in three have changed sleep patterns.

Many say they "nearly always" feel stressed in juggling their responsibilities for helping family with disabilities and other family and work responsibilities. Many say that occasional relief would enable them to continue providing help. However, supports are often unavailable or are not provided in a way that meets the family's needs.

Family breakdowns are more prevalent due to these strains, as evidenced by the fact that children with disabilities are more likely to live in step-families, single-parent families and foster families (one in three compared to one in four children without disabilities).

### 2. Eligibility criteria

In their search for supports and services, families often encounter rigid eligibility criteria that are insensitive to their needs and circumstances. Criteria can restrict their ability to be fully engaged in their communities and to have a life independent of their caregiving responsibilities.

For example, respite care gives family members a much-needed break. Access to respite is often inadequate and puts the health of caregivers, persons with disabilities and other family members at risk.

Family members consulted during our research called for a family-centred approach to supports and services.

## 3. Adequacy of family supports — in-home, community and employment-related

Family supports are especially critical at the time of diagnosis and immediately thereafter. Yet, families are often given no referrals to services and agencies that might support them through this difficult time.

One of the most critical strategic needs is around paid employment. Focus group respondents cited lack of flex time, and inadequate parental leave provisions and benefits that recognize caregiving responsibilities as key issues. Caregiving often affects their paid work activities, e.g. changed hours of work, being late or leaving early, missing days, turning down a job or a promotion, and/or affecting performance

## 4. Cost to families

Families largely finance the additional costs associated with caring for members with disabilities, severely straining family budgets. These costs include:

full- or part-time in-home care; respite care; prescription and non-prescription drugs; adaptive equipment and technology; special foods, clothing, medical and non-medical supplies; renovations and home modifications; adapted vehicles, special transportation or taxi services; transportation, hotel and meal costs for medical appointments with specialists; and childcare for siblings during medical appointments and emergencies.

Yet, many families caring for a person with disabilities do not have sufficient income to make these purchases, nor to provide for the optimal health and development of their family members. In fact, children and adults with disabilities, and their families, tend to be at the lower end of the income scale.

Family income is often lower because family members remain out of the paid workforce to provide care, and because inflexible workplace practices make it hard to keep a secure and better-paying job. As well, 46% of those helping a family member have directly related extra expenses.

Parents interviewed suggested these supports:

- income support that takes into consideration the true cost of raising a child with a disability;
- transitional aids for parents who wish to continue education or re-enter the paid workforce;
- assistance in obtaining appropriate, affordable, accessible housing;
- provision of affordable, high-quality inclusive childcare, especially for single parents;
- intensive early childhood education and childcare for younger children and childcare for older children and adolescents who still need support;
- a renewed commitment to inclusive childcare and education;
- access to a range of services such as respite care and therapy (e.g. occupational, physical, speech-language);
- advocacy and information supports;
- a central source for planning, coordination and transition services; and
- proper training for formal caregivers.

The Canadian Association of Family Resource Centres (2000) calls for these backup supports: parent/caregiver education and support; childcare and children's programs; health education and care; youth programs; and employment support.

# COMMUNITIES

## Introduction

A key finding of our research was that there are inadequate resources for the disability sector at the community level.

This has led to a shortage of trained voluntary and paid disability specialists, to delays and gaps in the availability and delivery of supports and services and accessible community infrastructures, and to a lack of capacity of local non-governmental organizations (NGOs) to engage in disability-related work.

Respondents from provincial/territorial ministries of social service spoke about the importance of a federal investment in the disability sector if any headway was to be made at the community level.

## Facts about Communities

- In 1991, 16% of Canadians had a disability. Of these 4.2 million people, 3.9 million were living in the community.
- 2.6 million adults help persons with disabilities with daily activities (1996).
- Only half of persons with disabilities have paid employment.
- Half of persons with disabilities are of working age (15-64), one third are 65 and older; 9% are age 14 and younger (some 378,000 children).
- Half of adults affected have a mild disability; one third have a moderate disability.
- Almost one third of Aboriginal adults report a disability, about twice the national average.
- Almost two million adults with disabilities need help with everyday activities.
- More than one million adults need aids and/or devices.
- Data on children is incomplete but more than 100,000 children are in special education.
- More than two million adults with disabilities regularly take medications for their condition.
- Some 400,000 adults with disabilities need modifications inside and/or outside their homes.
- 37% of working-age persons with disabilities (728,000 persons) need architectural, technological, human or work-routine accommodations.

## Policy Keys for Communities

### 1. Inclusiveness of mainstream community services — recreation, school, workplace, health care, transportation

Mainstream community-based programs and opportunities that can improve the participation of many persons with disabilities are often not available, are located too far away to be useful in any practical sense, or require reliance on inadequate transportation. Where people can get to these generic services, in many cases the services are inaccessible, unaffordable or unresponsive to need.

Difficulties in accessing mainstream services begin almost from birth. Childcare centres often will not accommodate a child with disabilities or do not have the resources to do so. Mainstream schools often fail to welcome and include children with disabilities.

Government officials in several jurisdictions reported insufficient financial and human resources for specialists and teaching assistants. Parents with the means are turning increasingly to distance education or home schooling.

Even where services and programs are available, it does not mean they will automatically be dedicated to persons with disabilities and their inclusion. For example, parents expressed frustration about teaching assistants who are assigned to general duty or who function like babysitters and manage exclusion rather than facilitating inclusion.

There is also a presumption that certain groups (e.g. those with intellectual disability) will simply not be going to college. If persons with disabilities do go on to post-secondary education, there are many questions about who is responsible for funding and providing needed supports.

Depressed rates of employment among persons needing various supports in the workplace reinforce the common sense notion that, where such supports are not available, people will have difficulty participating in the workplace — or in other community situations.

All focus groups reported that generic systems (e.g., recreation, education, training, employment) have difficulty addressing issues of disability and enabling people to access supports if necessary. Their capacity to include and support persons with disabilities needs to be strengthened.

This would involve: designing new facilities and programs that enable inclusion from the outset; adapting existing facilities and programs to remove barriers to participation; educating staff to recognize and eliminate biases in policies, programs and services that lead to marginalization and/or exclusion; identifying and challenging pervasive social attitudes, conditions and behaviours that contribute to these biases.

Lack of community resources such as accessible public transportation creates problems for persons with disabilities who want and need to access other community services such as health care, recreation and social activities. Transportation access is especially acute in northern, remote and rural areas.

Better access to regular public transportation would bring persons with disabilities more fully and clearly into the mainstream, helping to sensitize others to their needs and to their presence in the community.

## 2. Accountability for full citizenship and inclusion by community sectors and governments

Respondents across the country agreed that accountability mechanisms largely serve systems rather than persons with disabilities and their families. People want measures that assess how well their needs are being met and how well systems are serving those needs. They are asking for planning, coordination and other services that are accountable to persons with disabilities and to their families.

While efforts to include accountability frameworks in new federal, provincial and territorial initiatives were applauded, concerns were raised that measures developed may not be inclusive of persons with disabilities.

Respondents are asking for bias-free indicators that do not result in disability being equated with failure and deficit, and indicators of success that are inclusive of all persons.

Concerns were also raised about the difficulties of setting common standards and monitoring for successful outcomes in the context of regionalization and different jurisdictions.

Adults with disabilities expressed how they felt trapped within a system that they perceive as being accountable to no one. Some said they were given no option but to work in sheltered workshops and receive what they considered to be "slave-wages." They reported that no one was accountable for monitoring their ongoing development as persons, and their changing needs, skills and aptitudes.

## 3. Investment in human resource development in the disability support sector

Education and training are urgently needed to improve the understanding of disability-specific issues and to challenge negative attitudes and stereotypical perceptions of disability. This includes physicians, health professionals, teachers, educators, recreation leaders and job trainers.

Employers typically have little understanding of disability issues, accommodation processes or the potential of persons with disabilities in the workplace. Meanwhile, funding is scarce for community organizations in the disability sector that could provide awareness raising and consultations.

Furthermore, lack of funding for NGOs in the disability sector severely restrict their capacity to deliver supports and services to the community at large. This precludes, for example, much-needed training for agency staff and volunteers in recreation and other sectors.

Even for employees working in disability-specific service agencies, lack of training is an issue. There were calls for more respect for persons with disabilities and their families, and more progressive attitudes and "best practices."

Further, the low value attached to persons with disabilities has been translated into low value placed on paid work in the disability sector. So, wages, benefits and status are low, making it difficult to attract and retain quality workers.

Community education programs are needed at a broader level to educate the public, professionals, and the media; raise awareness; and give people the skills to recognize and eliminate bias.

## 4. Strategy for deinstitutionalizing persons with disabilities

Generally, there is no proactive, systematic, wide-scale strategy to move persons from institutions into the community. Similarly, there is no strategic reinvestment in needed supports for persons with disabilities who want to resume their lives in the community.

Indeed, pressures to institutionalize people have reportedly re-emerged. This applies especially to those living with Fetal Alcohol Syndrome/Effect, related drug and alcohol problems and at high risk of criminal offence. The funding focus on prevention and treatment in these areas is often not met with investment in disability supports and deinstitutionalization.

Advancing community inclusion requires funding and the transfer of knowledge and skills. It requires a move from overly medicalized arrangements to less-medicalized community-based options. It requires affordable, supported housing in the community if independent living is to be a viable option.

Funding arrangements tend to favour congregate living (special care, nursing and large group homes). However, population data show little demand in the disability community for this style of living.

Research shows much higher levels of social and economic inclusion where persons have access to self-managed and self-directed support in their own homes.

Social assistance is not keeping pace with rising rents, making it difficult for people to make the transition from their parents' homes to greater independence. Supported housing for younger persons is very difficult to obtain.

# TOWARDS A LEADING-EDGE APPROACH

A coordinated, comprehensive policy response is needed that will include:

- A state obligation to redress the historic disadvantage of persons with disabilities.
- Policies that meet Charter and other human rights and respect the dignity and self-determination of all persons.
- Disability supports that foster full participation, membership and inclusion of persons with disabilities.
- Collaboration among and within jurisdictions in policy, funding, monitoring, evaluation and information sharing.
- Policies that enable persons with disabilities and their families to determine their needs and best interests and to have control over how these are best met.
- Mechanisms to secure individualized funding as a way to give personal control over meeting needs and interests.
- Making the most of informal supports by supporting the family members and others who provide them.
- Fostering independent, community living.
- Investing in communities and local organizations to shift to more empowering, responsive modes of operation.
- Engaging the disability community in the policy process.

## Key priorities for action

- Increase the availability of affordable and responsive disability supports to individuals, especially those needing: more help with personal care and moving about at home; costly technical devices for hearing; oral or sign-language interpreters; wheelchairs/scooters; home modifications; accessible community transportation and workplaces.
- Increase the portability of individuals' disability supports across life situations, communities and jurisdictions.
- Ensure that family members have the financial, emotional and health support that they need to play their vital role.
- Strengthen the capacity of NGOs to provide responsive, affordable disability supports; and engage with governments in program design and in tracking investments in disability supports and outcomes.
- Create more innovative ways to use refundable tax credits, direct transfers, and the Employment Insurance, Child Tax Benefit and Canada Pension Plan systems.
- Create new programs to provide access to health and dental benefits for uninsured persons.
- Provide grants and loans to communities to improve access and inclusion of persons with disabilities in community programs, services and opportunities.
- Develop a new human resource strategy to ensure the availability of skilled, committed people to meet the demand for services in the disability sector.
- Ensure provinces and territories have the financial capacity to deliver on these priorities.
- Ensure the commitment of significant federal financial support to deliver on these priorities.

## Resources and Contacts

*Moving in Unison into Action,* The Roeher Institute

*Striking a New Balance,* The Roeher Institute

Council of Canadians with Disabilities and its member groups
www.pcs.mb.ca/~ccd/

Canadian Association for Community Living and its provincial, territorial and local affiliates
www.cacl.ca

People First of Canada, an organization promoting equality for all people who have been labelled.
www.interlog.com/~pfc/

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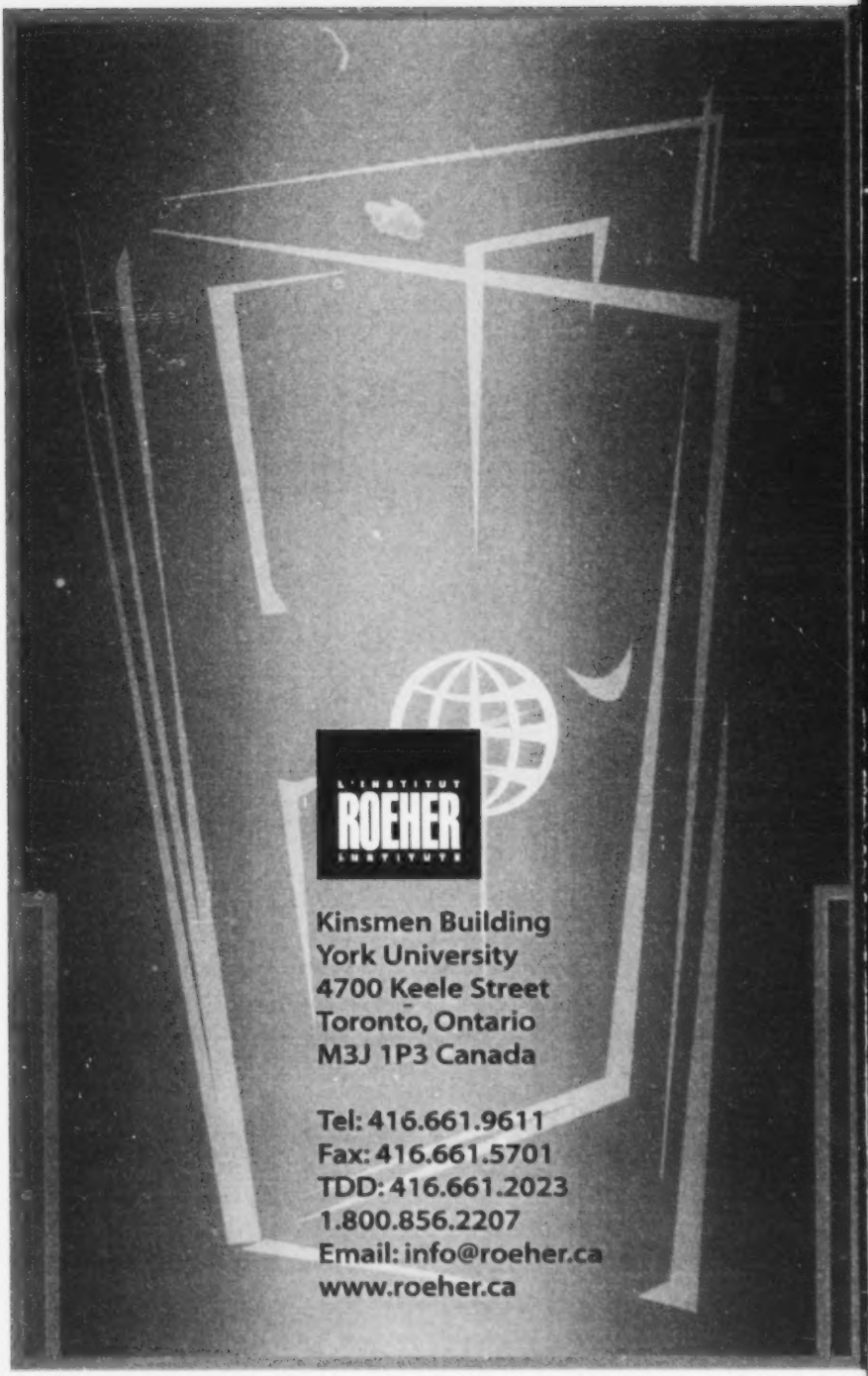
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